

Evaluating information prescriptions in two clinical environments

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APPENDIX A

Exit surveys

Breast cancer exit survey

[Insert patient # and name]

We'd like to ask you your opinions about information you received about your breast cancer and its treatment at Johns Hopkins. I'd like you to rate each question as excellent, very good, good, fair, poor, or does not apply.

1. How fully and clearly Johns Hopkins informed you about your *diagnosis*. Would you say that was excellent, very good, good, fair, or poor?

Excellent ☐ Very good ☐ Good ☐ Fair ☐ Poor ☐ NA ☐

2. How complete the information was that you received from Johns Hopkins about the different types of breast cancer surgery? Would you say that was excellent, very good, good, fair, or poor?

Excellent ☐ Very good ☐ Good ☐ Fair ☐ Poor ☐ NA ☐

3. How complete the information was that you received from Johns Hopkins about the possible benefits and harms from different types of breast cancer surgery?

Excellent ☐ Very good ☐ Good ☐ Fair ☐ Poor ☐ NA ☐

4. How fully Johns Hopkins informed you about the potential benefits and harm of radiation therapy?

Excellent ☐ Very good ☐ Good ☐ Fair ☐ Poor ☐ NA ☐

5. How fully Johns Hopkins informed you about the potential benefits and harm of adjuvant chemotherapy?

Excellent ☐ Very good ☐ Good ☐ Fair ☐ Poor ☐ NA ☐

6. How fully Johns Hopkins informed you about the potential benefits and harm of anti-estrogen therapy (such as tamoxifen or arimidex)?

Excellent ☐ Very good ☐ Good ☐ Fair ☐ Poor ☐ NA ☐

7. How well Johns Hopkins informed you about the psychological and social problems caused by breast cancer and its treatment?

Excellent ☐ Very good ☐ Good ☐ Fair ☐ Poor ☐ NA ☐

8. How well Johns Hopkins informed about services (both at Johns Hopkins and in the community) for dealing with the psychological and social problems caused by breast cancer and its treatment? Would you say that was excellent, very good, good, fair, poor, or does not apply to me?

Excellent ☐ Very good ☐ Good ☐ Fair ☐ Poor ☐ NA ☐

9. I'd like you to give an overall rating of how well Johns Hopkins educated you about your breast cancer and its treatment. This includes all sources of education that you experienced at Johns Hopkins (i.e., staff, books, pamphlets, audiovisual materials, Internet, or web, etc.)

Excellent ☐ Very good ☐ Good ☐ Fair ☐ Poor ☐ NA ☐

Comparison of staff information

We would like to get your opinions about information you received about your cancer diagnosis and treatment from several different kinds of people or sources. I would like you to rate the quality of information from each group of people as excellent, very good, good fair, poor, or does not apply to me. If you do not remember receiving any information from the type of person or place I ask about, just let me know that.

1. How would you rate the information you received about your breast cancer and its treatment from *doctors at Johns Hopkins*?

Excellent ☐ Very good ☐ Good ☐ Fair ☐ Poor ☐ NA ☐

2. How would you rate the information you received about your breast cancer and its treatment from *nurses at Johns Hopkins*?

Excellent ☐ Very good ☐ Good ☐ Fair ☐ Poor ☐ NA ☐

3. How would you rate the information you received about your breast cancer and its treatment from *librarians at Johns Hopkins*?

Excellent ☐ Very good ☐ Good ☐ Fair ☐ Poor ☐ NA ☐

4. How would you rate the information on the *Johns Hopkins website*?

Excellent ☐ Very good ☐ Good ☐ Fair ☐ Poor ☐ NA ☐

5. How would you rate the information you received from *other Breast Center staff* at Johns Hopkins about your breast cancer and its treatment?

Excellent ☐ Very good ☐ Good ☐ Fair ☐ Poor ☐ NA ☐

6. How would you rate the information you received about your breast cancer and its treatment from doctors, nurses, or other medical people *outside of Johns Hopkins*?

Excellent ☐ Very good ☐ Good ☐ Fair ☐ Poor ☐ NA ☐

7. How would you rate the information you received about your breast cancer and its treatment from your *family and friends*?

Excellent ☐ Very good ☐ Good ☐ Fair ☐ Poor ☐ NA ☐

Some people find websites on their own or in other ways besides being told about them by doctors, nurses, librarians, or other staff at Johns Hopkins or getting a link from the Johns Hopkins.

8. Did you find any websites on your own or in other ways?

Yes ☐ No ☐ Not answered ☐

If yes,

9. How would you rate the information you found on these websites that you found in other ways?

Excellent ☐ Very good ☐ Good ☐ Fair ☐ Poor ☐ NA ☐

Resource use

And now I have a few more questions about your work and activities since you we saw you at the clinic on [date of enrollment]. If you have used the diary we gave you to help with this, could you have it nearby when I ask these questions.

1. What is your occupation? _____

2. Have you taken time off from work since [date of enrollment]?

Yes ☐ No ☐ Not answered ☐

If yes,

How many hours or days? ____

3. Have you required assistance with daily living (related to mobility, personal care, dressing, eating and drinking, home management, or activities like these)?

Yes ☐ No ☐ Not answered ☐

If yes,

Did you hire someone to help you?

Yes ☐ No ☐ Not answered ☐

Did a family member take off from work to help you?

Yes ☐ No ☐ Not answered ☐

How much time did they take off? ____

4. Did you contact your doctor since [date of enrollment]? Your diary may help you with answering this. Take your time.

Yes ☐ No ☐ Not answered ☐

If yes,

How many times? ____

How much time did you spend reaching and talking to your doctor? ____

5. Did you contact a clinic nurse since [date of enrollment]? Your diary may help you with answering this. Take your time.

Yes ☐ No ☐ Not answered ☐

If yes,

How many times? ____

How much time did you spend reaching and talking to your nurse? _____

6. Did you contact a librarian since [date of enrollment]? Your diary may help you with answering this. Take your time.

Yes ☐ No ☐ Not answered ☐ NA ☐

If yes,

How many times? ____

How much time did you spend reaching and talking to your librarian? _____

7. Did you use the following website "Breast Cancer Resources" to find information about your condition since [insert date]? Your diary may help you with answering this.

Yes ☐ No ☐

If yes,

How many times? ____

How much time did you spend doing this? _____

8. Were you admitted to the hospital at any time since [date of enrollment]?

Yes ☐ No ☐ Not answered ☐

Impact of information

General impact of information

We are interested in how you used the information you got at Johns Hopkins and how that information affected you, either in a good or a bad way. Can you tell us how the information received affected you?

Impact on feelings

Follow-up: Can you say anything more about *how information you got at Johns Hopkins about your breast cancer or its treatment made you feel*?

Probes: *[if not covered]*

How did the information you got at Johns Hopkins affect your feelings?

Did it worry you or cause you anxiety?

Yes ☐ No ☐ Not answered ☐

Did it reassure you?

Yes ☐ No ☐ Not answered ☐

Is there any other way that the information affected how you felt?

Impact on decisions and behavior

We are interested in whether the information you got at Johns Hopkins changed your decisions about your breast cancer. Can you tell us anything about that?

Probes: *[if not covered]*

Did information you received at Johns Hopkins help you choose the type of surgery you would have to remove the breast cancer? _____ NA ☐

Did information you receive at Johns Hopkins help you choose whether to have breast reconstruction? _____

[If you chose to have breast reconstruction, skip next question.] NA ☐

[If did not have breast reconstruction:]

Did information you received at Johns Hopkins help you decide what type of prosthesis to purchase?

Yes ☐ No ☐ Not answered ☐ NA ☐

Can you tell me more about that?

Did information received help you choose whether to have chemotherapy?

Yes ☐ No ☐ Not answered ☐ NA ☐

[If yes and no elaboration:]

Can you tell me more about that?

Did information you received at Johns Hopkins help you choose whether to have radiation therapy?

[If yes and no elaboration:]

Yes ☐ No ☐ Not answered ☐ NA ☐

[If yes and no elaboration:]

Can you tell me more about that?

Did information you received at Johns Hopkins help you choose whether to have anti-estrogen therapy?

Yes ☐ No ☐ Not answered ☐ NA ☐

Can you tell me more about that?

Did information you received at Johns Hopkins assist you in finding help or coping with social or psychological problems?

Yes ☐ No ☐ Not answered ☐ NA ☐

Can you tell me more about that?

Did you join a support group?

Yes ☐ No ☐ Not answered ☐

If you joined a support group: What made you decide to do join a support group? _____

How did you find out about the support group? _____

Did anyone suggest that you join a support group? . Who? _____

Who helped you the most with psychological or social problems? _____

If it was a professional such as psychologist or social worker or name of a person or an organization, how did you find ____?

Did anyone suggest that you go to ____?

Yes ☐ No ☐ Not answered ☐

Have you seen anyone to help with psychological or social problems?

Yes ☐ No ☐ Not answered ☐

[If yes:]

Why did you decide to do that? _____

How did you find the person you went to? _____

Is there any other way that the information you received at Johns Hopkins affected things you chose to do about your breast cancer?

Now I'm going to ask you some about your quality of life. How would you say your quality of life was affected by the information you received at Johns Hopkins about your breast cancer or its treatment?

Is there anything more you can tell me about that, about how your quality of life was affected by the information you got at Johns Hopkins?

"Can you tell me more about that?"

Are there any ways that information you got at Johns Hopkins reduced your quality of life?

Are there any ways that information you got at Johns Hopkins made your quality of life better?

Treatment: Are you currently in:

Chemotherapy ☐ Hormonal therapy ☐ Neither ☐

Neonatal intensive care unity survey

[Insert patient # and name]

We'd like to ask you your opinions about information you received about your child's neonatal intensive care unit (NICU) stay and treatment and care for prematurity at Johns Hopkins.

Please rate each question as excellent, very good, good, fair, poor, or does not apply (NA).

1. Johns Hopkins completely and clearly informed me about my baby's *diagnoses*.

Completely agree ☐ Mostly agree ☐ Slightly agree ☐ Slightly disagree ☐ Mostly disagree ☐ NA ☐

2. Johns Hopkins completely and clearly informed me about the different *treatments* and the care my baby had for prematurity?

Completely agree ☐ Mostly agree ☐ Slightly agree ☐ Slightly disagree ☐ Mostly disagree ☐ NA ☐

3. Johns Hopkins completely and clearly informed me about the possible benefits and harms from different types of treatment for prematurity?

Completely agree ☐ Mostly agree ☐ Slightly agree ☐ Slightly disagree ☐ Mostly disagree ☐ NA ☐

4. Johns Hopkins completely and clearly informed me about the potential benefits and harm of ventilator (respirator) treatment?

Completely agree ☐ Mostly agree ☐ Slightly agree ☐ Slightly disagree ☐ Mostly disagree ☐ NA ☐

5. Johns Hopkins completely and clearly informed me about the potential benefits and harm of any surgery my baby needed or had?

Completely agree ☐ Mostly agree ☐ Slightly agree ☐ Slightly disagree ☐ Mostly disagree ☐ NA ☐

6. Johns Hopkins completely and clearly informed me about the potential benefits and harm of medications my baby was on.

Completely agree ☐ Mostly agree ☐ Slightly agree ☐ Slightly disagree ☐ Mostly disagree ☐ NA ☐

7. Johns Hopkins completely and clearly informed me about developmental delay my child may experience.

Completely agree ☐ Mostly agree ☐ Slightly agree ☐ Slightly disagree ☐ Mostly disagree ☐ NA ☐

8. Johns Hopkins completely and clearly informed me about community services available for helping with developmental delays that my child may experience.

Completely agree ☐ Mostly agree ☐ Slightly agree ☐ Slightly disagree ☐ Mostly disagree ☐ NA ☐

9. Johns Hopkins taught me how to care for my baby before discharge or transfer.

Completely agree ☐ Mostly agree ☐ Slightly agree ☐ Slightly disagree ☐ Mostly disagree ☐ NA ☐

10. Overall, Johns Hopkins educated me about my baby's prematurity and its treatment and care. This includes all sources of education that I experienced at Johns Hopkins (for example, from staff, books, pamphlets, audiovisual materials, Internet, or web, etc.).

Completely agree ☐ Mostly agree ☐ Slightly agree ☐ Slightly disagree ☐ Mostly disagree ☐ NA ☐

Comparison of staff information

We would like to get your opinions about information you received about your child's prematurity from several different kinds of people or sources. Would you rate the quality of information from each group of people as excellent, very good, good fair, poor, or does not apply to me (NA). If you do not remember receiving any information from the type of person or place asked about, check NA.

1. How would you rate the information you received about your child's prematurity from *doctors and neonatal nurse practitioners at Johns Hopkins*?

Excellent ☐ Very good ☐ Good ☐ Fair ☐ Poor ☐ NA ☐

2. How would you rate the information you received about your child's prematurity from *nurses at Johns Hopkins*?

Excellent ☐ Very good ☐ Good ☐ Fair ☐ Poor ☐ NA ☐

3. How would you rate the information you received about your child's prematurity from *librarians at Johns Hopkins*?

Excellent ☐ Very good ☐ Good ☐ Fair ☐ Poor ☐ NA ☐

4. How would you rate the information on the *Johns Hopkins website*?

Excellent ☐ Very good ☐ Good ☐ Fair ☐ Poor ☐ NA ☐

5. How would you rate the information you received from *other NICU staff* at Johns Hopkins about your child's prematurity and its care and treatment?

Excellent ☐ Very good ☐ Good ☐ Fair ☐ Poor ☐ NA ☐

6. How would you rate the information you received about your child's prematurity and its care and treatment from doctors, nurses, or other medical people *outside of Johns Hopkins*?

Excellent ☐ Very good ☐ Good ☐ Fair ☐ Poor ☐ NA ☐

7. How would you rate the information you received about your child's prematurity from your *family and friends*?

Excellent ☐ Very good ☐ Good ☐ Fair ☐ Poor ☐ NA ☐

Some people find websites on their own or from other sources, for example, from friends, family, or TV, besides being told about them by doctors, nurses, librarians, or other staff at Johns Hopkins or getting a link from the Johns Hopkins website called: "Infant Prematurity Resources: A Welch Medical Library Patient Information Service."

8. Did you find any websites on your own or from other sources such as friends, family, or TV?
Yes ☐ No ☐

If yes,

9. How would you rate the information you found on these websites that you found in other ways?

Excellent ☐ Very good ☐ Good ☐ Fair ☐ Poor ☐ NA ☐

Resource use

And now we have a few more questions about your work and activities since we saw you on [date of enrollment]. If you have used a diary, it may help you recall these.

1. What is your occupation? _____

2. Have you taken time off from work since [date of enrollment]?

Yes ☐ No ☐

If yes, How many hours or days?

3. Have you required assistance with daily living (related to child care, home management, or activities like these)?

Yes ☐ No ☐

If yes,

Did you hire someone to help you?

Yes ☐ No ☐

Did a family member take off from work to help you?

Yes ☐ No ☐

How much time did they take off? ____

4. Did you contact a *NICU doctor* since [date of enrollment]? Your diary may help you with answering this.

Yes ☐ No ☐

If yes,

How many times? ____

How much time did you spend reaching and talking to your doctor? ____

5. Did you contact a *NICU nurse* since [date of enrollment]? Your diary may help you with answering this.

Yes ☐ No ☐

If yes,

How many times? ____

How much time did you spend reaching and talking to your nurse? _____

6. Did you contact a *librarian* since [date of enrollment]? Your diary may help you with answering this.

Yes ☐ No ☐

If yes,

How many times? ____

How much time did you spend reaching and talking to your librarian? _____

7. Did you use the following website called "Infant Prematurity Resources: a Welch Medical Library Patient Information Service" to find information about your condition since [date of enrollment]? Your diary may help you with answering this.

Yes ☐ No ☐

If yes,

How many times? ____

How much time did you spend doing this? _____

Impact of information

General impact of information

We are interested in how you used the information you got at Johns Hopkins and how that information affected you, either in a good or a bad way. Can you tell us how the information received affected you?

Impact on feelings

How did the information you got at Johns Hopkins affect your feelings? _____

Did it worry you or cause you anxiety?

Yes ☐ No ☐

Did it reassure you?

Yes ☐ No ☐

Is there any other way that the information affected how you felt? _____

Impact on decisions and behavior

We are interested in whether the information you got at Johns Hopkins changed your decisions about your child's prematurity and its treatment and care. Can you tell us anything about that?

Did information you received at Johns Hopkins help you choose whether your child should have any surgery?

Yes ☐ No ☐ Not applicable ☐

Would you like to comment on that? _____

Did information you received at Johns Hopkins assist you, as the parent of a premature infant, in finding help or coping with social or psychological problems?

Yes ☐ No ☐ Not applicable ☐

Would you like to comment on that? _____

Did you join a support group?

Yes ☐ No ☐

If you joined a support group: What made you decide to do join a support group? _____

How did you find out about the support group? _____

Did anyone suggest that you join a support group? _Who? _____

Who helped you the most with psychological or social problems? _____

If it was a professional such as psychologist or social worker or name of a person or an organization,

How did you find _____?

Did anyone suggest that you go to _____?

Yes ☐ No ☐ Not applicable ☐

Have you seen anyone to help with psychological or social problems?

Yes ☐ No ☐ Not applicable ☐

[If yes:] Why did you decide to do that? _____

[If yes] How did you find the person you went to? _____
Is there any *other* way that the information you received at Johns Hopkins affected things you
chose to do about your baby's prematurity and problems related to that?

How would you say your quality of life was affected by the information you received at Johns
Hopkins about your child's prematurity or its treatment?

Are there any ways that information you got at Johns Hopkins *reduced* your quality of life?

Are there any ways that information you got at Johns Hopkins made your quality of life *better*?

Treatment: Is your baby currently

In the hospital? _____

In the intensive care unit? ____

On a ventilator? _____

On any medical treatments or medications? _

Other comments: _____

Thank you for taking the time to answer these questions. Your participation is appreciated.